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Pressure placed on paediatric haematopoietic stem cell donors: Views from health professionals.

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## 1. Title Page

**Title:** Pressure Placed on Paediatric Haematopoietic Stem Cell Donors: Views from Health Professionals

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## 2. Abstract and Keywords

**Aim:** Paediatric haematopoietic stem cell donors undergo non-therapeutic procedures and endure known and unknown physical and psychosocial risks for the benefit of a family member. One ethical concern is the risk they may be pressured by parents or health professionals to act as a donor. This paper adds to what is known about this topic by presenting the views of health professionals. **Methods:** This qualitative study involved semi-structured interviews with 14 health professionals in Australasia experienced in dealing with paediatric donors. Transcripts were analysed using established qualitative methodologies. **Results:** Health professionals considered that some paediatric donors experience pressure to donate. Situations were identified that were likely to increase the risk of pressure being placed on donors and views were expressed about the ethical ‘appropriateness’ of these practices within the family setting. **Conclusions:** Children may be subject to pressure from family and health professionals to be tested and act as donors, Therefore, our ethical obligation to these children extends to implementing donor focused processes – including independent health professionals and the appointment of a donor advocate – to assist in detecting and addressing instances of inappropriate pressure being placed on a child.

### What is already known on this topic

- Tissue-matched children are sometimes used as allogeneic stem cell donors for sick siblings.
- Small scale qualitative studies report that some child donors experience pressure to donate from parents and health professionals.

- Existing guidelines suggest that independent health professionals and donor advocates be appointed for paediatric donors.

**What this paper adds**

- This paper examines the ethically concerning issue of children experiencing pressure to act as a stem cell donor through a qualitative study of health professionals' views.
- Specific situations are identified that may increase the risk of pressure being placed on a child to take on the donor role.
- A child donor's position within the family can influence health professionals' perceptions regarding the appropriateness of some forms of parental pressure placed on a child.

**Key words:** qualitative research; bone marrow transplantation; siblings; paediatrics; ethics

### **3. Pressure Placed on Paediatric Haematopoietic Stem Cell Donors: Views from Health Professionals**

#### **Introduction**

It is accepted medical practice that children can act as allogeneic stem cell donors for tissue-matched sick recipients. However, this practice raises a number of ethical issues. Concerns arise due to the inherent vulnerability of paediatric donors, the non-therapeutic nature of the intervention (bone marrow harvest or, less commonly, aphaeresis) and the physical and psychological risks associated with donating.<sup>1,2,3</sup> These impose ethical obligations on health professionals to implement special measures to benefit and protect these children; something that has been recognised by medical organisations.<sup>3,4</sup>

One ethical concern is the risk that tissue-matched children may be pressured – by parents, family or health professionals – to take on the donor role.<sup>5,6,7</sup> Relevant behaviour could realistically span ‘request, reasoning, persuasion, barter, bargaining, begging, gentle prodding, enticement, selective information, manipulation, deceiving, blackmail, threat, [or] even various forms of physical force’.<sup>8</sup> Along this continuum it is not clearly apparent at what point such actions move from being ‘acceptable’ to being considered ethically dubious.

While for younger donors the decision will ultimately be that of a parent, existing guidelines suggest that, where possible, children should agree or assent.<sup>3,4,9,10</sup> This approach is consistent with granting children participatory rights matched to their developing capacities – something also recognised in international law.<sup>11</sup> Consistent objections to donation by older children (and, some suggest, younger children<sup>9,12</sup>) should

also be respected.<sup>3,4</sup> Given the perceived need for a potential donor to agree and not object, this may lead to others pressuring them to acquiesce or express agreement.

Parents or health professionals may exert pressure as a consequence of their conflicted position.<sup>3</sup> Parents of potential donors will necessarily be conflicted as removal of tissue from a child will be for treatment of another family member, most commonly the child's sibling or in rarer cases a parent or cousin. How exactly 'does a parent make an impartial evaluation' of the interests of their child when the life of another family member is at risk?<sup>13,14</sup> For health professionals working in accredited departments, the FACT-JACIE standards, together with other guidelines, now require independent medical evaluation of all donors.<sup>3,4,15</sup> However, this may not always occur.<sup>3,17</sup> Health professionals who face a conflict of interest in treating both recipients and donors may inadvertently pressure a child to donate.

Qualitative studies examining this issue are limited, but do identify that some child sibling donors do experience pressure from family and health professionals. Macleod reported that a third of donors interviewed (n=15) experienced 'forced no choice' in their decision, reporting pressure from their families or doctors.<sup>18</sup> In that study, instances of children feeling unable to say 'no' to being a donor because of pressure from others ('forced no choice') were indicated by donors using statements such as 'guilt', 'propaganda', 'lucky one', 'bribed', 'privileged', 'conned' and 'knew what they had to do to get what they wanted'. Other studies also report findings of child donors experiencing pressure from parents.<sup>19,20,21</sup>

The aim of this paper is to investigate the views of relevant health professionals regarding pressure on potential child donors. Their views are important as they act as ‘gatekeepers’ to children donating, have generally been involved in multiple instances of paediatric donation and therefore have observed or experienced a range of reactions from donors and their families. They are also integral in implementing changes in clinical practice to benefit child donors.

The findings here add to the growing body of literature on child donors<sup>22</sup> and assist in identifying the types of situations that may be more likely to lead to potential paediatric donors experiencing external pressure. These findings allow those appointed to advocate for paediatric donors to be better prepared in addressing their needs.

## **Material and Method**

Fourteen health professionals from Australasia, whose scope of work currently or formerly included dealing with paediatric donors, took part in this study. See Table I for participant characteristics.

Access came about through direct contact with health professionals who had published on paediatric tissue donation, the Australian and New Zealand Children’s Haematology/Oncology Group circulating information about the study, and participants contacting people they knew to determine their interest in being involved and being contacted by the author. The University of Sydney human research ethics committee approved this study and informed consent was obtained from all participants. Semi-structured in-depth interviews were conducted by the author with all participants between November 2011 – July 2012.

### *Procedure and Analysis*

The findings in this paper come from a broader study undertaken as doctoral research that investigated health professionals' views regarding regulation, ethics and child donors. The results in this paper focus on data from that broader study relevant to the issue of children experiencing pressure to act as a stem cell donor. Initial interview topics were formulated after reviewing relevant ethical and legal literature and, as interviews progressed, additional topics emerged as relevant and were included in subsequent interviews. Thematic saturation was apparent after thirteen interviews. The themes identified as relevant to this paper are discussed below and summarised in Table II.

The interviews were recorded with consent and transcribed verbatim by the author. The transcripts were coded by the author using categories developed deductively and inductively through an iterative process of considering concepts in the literature, and the unfolding interview data.<sup>23</sup> Both initial manual coding and coding through QSR-NVivo 9 (at a later date) was used for the first five transcripts. This allowed for familiarity with the data and categories and provided an opportunity to verify consistency of coding by the author. Later transcripts were coded solely through NVivo. NVivo was used to retrieve data assigned to the same or related codes allowing for assimilation into matrices to determine themes, patterns and findings from the data.<sup>24</sup> This research was undertaken solely by the author, but under the close oversight of senior colleagues experienced in qualitative research and validation of findings.

### **Results**



The fieldwork indicates participants' perceptions that some potential donors do experience pressure from others to donate. Participants expressed views about situations that are likely to increase the chance of pressure being exerted and the 'appropriateness' of some practices within the context of the family. The main themes are outlined in Table II.

### ***The presumption that children will be donors***

Some participants expressed the view that parents will often expect their healthy children to donate. While an expectation of donation may not be equivalent to direct pressure, it may create an environment where a child may be, implicitly, *expected* to conform. Two clinicians noted that parents generally expect that children will donate.

I've observed over and over again how parents just take it for granted that... 'one of my children needs a transplantation – it goes without saying that the other one will be a donor', without too much discussion...

One clinician noted that health professionals could also sometimes assume that children will be willing to act as donors for siblings.

### ***Pressure placed on child donors***

#### ***Pressure from parents***

Three clinicians had encountered circumstances where they considered that parental pressure had been exerted on a child to act as a donor. Other participants had not directly observed instances of pressure from parents, but considered the risk of such pressure to be real.

One participant, in recognising the difficulties that lead parents to pressure a tissue-matched child to donate, described the situation parents are placed in that makes them want their child to '*please do this*':

[Parents are] looking for something that will work and of course bone marrow transplant generally means other treatment hasn't worked... How do you remove that? 'It's fine if you don't want to do it that's fine he'll just die, don't worry'. It's not really an optional path. Not in reality...

Where such sentiments are expressed to children – and such a case is documented in Packman's study – psychologically detrimental outcomes in a child due to such 'emotional blackmail' are unsurprising.<sup>21</sup>

The situation of conflict between parents was identified as being particularly likely to create pressure on a child to donate. Four participants noted that conflict regarding treatment options for the sick child was relatively common; this often related to the decision of whether to opt for a transplant. Three clinicians agreed that conflict at this stage was far more likely than disagreement later regarding whether another child should donate. Where earlier disagreements were resolved in favour of having the transplant, one practitioner noted the decision to have another child act as a donor appeared comparatively easy.

Two clinicians also noted that, in the rare situation where a child may act as a donor for a parent, the chances of pressure being placed on a child are likely to increase.

One problematic situation identified here and in a previous study, was a failure to have a formalised consent procedure for tissue-typing where the implications of results were

thoroughly communicated to the family before testing occurred.<sup>22</sup> One participant noted that this could lead to problems, including a situation of immediate pressure being placed on a tissue-matched child, if results are reported back to the family in an informal setting with one child being identified as tissue-matched.

### *Pressure from health professionals*

Seven participants recognised that, in the absence of independent health professionals for the donor and recipient, a conflict of interest arises that may bias medical staff leading to them (inadvertently) pressuring tissue-matched children to donate.<sup>25</sup> One clinician noted such pressure was often not going to ‘*be a conscious thing*’ and likened it to a researcher not wanting to ‘*lose that opportunity*’ when attempting to complete a research program.

In addition, in the hypothetical situation of a late withdrawal of assent or consent by the donor, after the recipient had undergone myeloablative therapy, one participant stated ‘*we try very hard to coerce them in that situation... that late withdrawal of consent... would not be a fair thing*’.

### ***Familial obligation and the ‘appropriateness’ of pressure within the family***

#### *Family obligation*

Five clinicians discussed the donor child in the context of his or her ‘family unit’, or the obligations that this may give rise to in this setting. Such comments are consistent with ethical literature identifying familial obligations or the existence of intimate relationships between recipients, donors and parents, as one prominent ethical justification for children donating.<sup>25,26,27,28</sup>

Two clinicians raised the concept of family obligation, noting that most potential donors would feel obligated to donate to a family member. Another noted that, in the past, strong notions of family obligation may have led to an expectation by others of tissue-matched family members donating.

One clinician voiced the conceptual difficulty in reconciling the ‘*relational*’ nature of decision-making within family units, and respecting the autonomy of individuals.

[T]here is a broad social, legal and moral recognition that [family members] have to be treated... as individuals. But... [t]o say that the decision made for one child to be a donor is irrelevant to everything else happening in the family is just as stupid as to say, well the death of the child with illness is irrelevant to the interests of everybody else in the family... So this notion of relational autonomy, philosophically is an appealing one, but it’s also a very dangerous one. [Because] relational autonomy blurs the margins between individuals as well...

*‘Appropriate’ pressure?*

The statements of four interviewees suggest that always viewing parental pressure on a donor child negatively was, in fact, a rather simplistic interpretation. Instead, some types of pressure or the resolution of difficult donor issues within families were seen to be ‘*appropriate*’ or more understandable in the context of the family.

One clinician compared sibling donation to other realms of family life suggesting that having a coercive environment where there was an expectation that a teenager would act as a donor was ‘*not necessarily a bad thing because I think that’s sort of a realistic manifestation of the way that families exist in every domain*’.

Another practitioner, in apparently justifying the use of family pressure in one instance, noted that an additional rationale was the need to protect that child from suffering psychologically in the future: *‘imagine getting to 21 and you’ve got your dead brother or sister and you knew that you were the reason’*.

## **Discussion**

The findings in this paper add to the existing literature on donor children and how their needs have sometimes been forgotten.<sup>22</sup> The fieldwork has revealed that some tissue-matched children are pressured to donate and health professionals identify such pressure as an issue of realistic concern. Such pressure can also extend to potential tissue-matched children prior to testing and the findings here can also relate to this earlier step.

The ‘relational’ nature of intimate families and the concept of ‘family obligation’ surfaced as justification for some forms of ‘appropriate’ pressure placed on potential donors from within families. Some health professionals appeared to justify the use of child donors based on the fact that the interests of family members are dependent or intertwined. This also appears to influence some participants’ opinions about the ‘acceptability’ of some forms of pressure placed on children by parents. A similar distinction between ‘acceptable coercion’ and ‘unacceptable compulsion’ has been identified in studies involving anorexic patients.<sup>8</sup> If such a distinction should be drawn in this paediatric donor population, how to identify what is acceptable and what is not is a difficult task for health professionals, with no clear line separating the two types of conduct. However, these difficulties do not obviate health professionals’ obligations to children to minimise potential harm to them in undergoing non-therapeutic tests and, potentially, a tissue harvest.

Another significant finding is that specific situations (see Table III) were identified as *increasing* the likelihood of pressure being placed on a potential donor child by parents or health professionals. While knowledge of these circumstances allows those advocating on behalf of potential donor children to be more alert to the risk of external pressure in these situations, it also allows us to consider how better to address the risk of pressure or minimise the occasions in which these situations may occur. Below, recommendations are made that may assist in the specific situations identified in Table III.

Taken together, the ‘normalisation’ of pressure on potential donors within families and the fact that health professionals consider external pressure to be a realistic possibility, provide reasons in favour of adopting practices to minimise pressure being placed on potential child donors, i.e. improved pre-tissue-typing consent procedures, better communication and the involvement of a donor advocate.

Practices surrounding consent for tissue-typing and how results of such tests are communicated ought to be altered to minimise stress and prevent the risk of undue and immediate pressure being placed on an identified tissue-matched child.<sup>22</sup> This requires, *prior* to testing occurring, full disclosure and discussion with parents and children of the implications and consequences of testing and finding a positive match.

Various other mechanisms have been suggested to protect donor children. Some commentators have suggested introducing a routine external review process involving courts, independent tribunals or review committees to independently vet the decision that a child act as a donor.<sup>28,29</sup> However, this is considered by many to be unnecessary and too onerous a requirement on the family at what is already a difficult time.<sup>30,31,32</sup> Perhaps more

practically useful would be to follow recommendations to have someone independent for a child to confide in and who will exclusively champion their interests throughout testing and donation.<sup>3,4</sup> In particular, the American Academy of Pediatrics recommends an independent donor advocate be appointed whose primary task is to help donors and their parents understand the process of donation and to protect and promote the interests and well-being of the donor.<sup>3</sup> Appointing independent health professionals and donor advocates as part of better donor-focused processes is likely to result in increased detection of inappropriate pressure, particularly if health professionals are alert to specific circumstances likely to increase the chance of pressure on a child, such as earlier parental conflict which is resolved in favour of transplantation and the rare circumstance where a parent is the intended recipient. The presence of such an advocate may also help to avoid the situation where a child withdraws their consent or assent after conditioning of the recipient has occurred. As indicated above, this situation brings sharply into focus the extreme need of the recipient against respecting the autonomy, or emerging autonomy, of a potential donor child and places health professionals in an extremely difficult position. Such late withdrawal by a child may indicate an unwillingness to donate that was previously not recognised or which a child felt unable to articulate at an earlier stage. Having a confidante and better support for the child at an earlier stage would hopefully help avoid such ethically challenging situations. Where donor advocates are appointed, their role should include monitoring for the presence of inappropriate pressure on the potential donor and, where possible, taking steps to address such problems.

This study is limited by a failure to include the views of child donors. In addition, the scope of the role of donor advocates and how those appointed to this role carry out their

responsibilities, particularly in the circumstance where inappropriate pressure is detected, requires further research.



#### **4. Acknowledgments**

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#### **Conflict of Interest**

No conflict of interest.

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## 8. Tables

**Table I. Positions held by interview participants**

<i>Description of participant's position at the time of interview</i>	<i>Number interviewed</i>
Consultant medical practitioners practising in paediatric hospitals and involved with child donors	8
Consultant medical practitioners formerly involved with child donors	4
Transplant nurse involved with child donors	1
Social worker formerly involved with child donors	1

**Table II. Summary of results – main theme**

<i>Theme</i>	<i>Description</i>	<i>Examples from data</i>
Expectation of donation	Parents and health professionals may assume that a tissue-matched child sibling will act as a donor.	<ul style="list-style-type: none"> <li>• ‘I think parents essentially take it for granted that the siblings will be happy to donate’</li> </ul>
Likelihood of pressure	<p>Pressure from parents</p> <ul style="list-style-type: none"> <li>• Actual pressure observed</li> <li>• A realistic concern</li> <li>• Where earlier parental conflict resolved in favour of transplant</li> <li>• Where parent is the recipient</li> <li>• Where pre-tissue-typing procedures are lacking</li> </ul> <p>Pressure from health professionals</p> <ul style="list-style-type: none"> <li>• Where lack of independent health professionals</li> <li>• Where late withdrawal of agreement to act as donor</li> </ul>	<ul style="list-style-type: none"> <li>• ‘I remember a little girl who was absolutely scared to death to go into theatre... but her parents were... making a lot of pressure and the committee and the anaesthetist and everyone.’</li> <li>• ‘I’ve heard a lot more about that from the adult sector. Maybe that’s because they’re doing a whole lot more transplants than what we’re doing down here, I don’t know, but, um... I think it probably is, as much, it’s as much an issue with adults as with kids. .</li> <li>• ‘everybody is more invested in that kid being the donor. So the... potential for that child... opting out? Very small...[B]ecause the coercive environment of expectation is gonna be massive in that sort of setting.’</li> <li>• ‘I think immediately when their own health is on the line it’s going to have to influence the potential coercion’.</li> <li>• ‘I think there is a problem with that [tissue-typing] consent process because of the implications of who’s able or who’s not able to donate’.</li> <li>• ‘we as the people looking after the patient have a bit of a vested interest and there’s always the risk that we could be seen to be coercing’</li> <li>• ‘we explain that and say it fairly strongly, that if the recipient’s had conditioning of their bone marrow and they are the only appropriate donor, that is actually not ok not to consent at that stage’.</li> </ul>
Justification for ‘acceptable’ pressure	<ul style="list-style-type: none"> <li>• Family obligation and the relational nature of decision-making within families.</li> <li>• The ‘appropriateness’ of some forms of pressure in the family setting was recognised.</li> </ul>	<ul style="list-style-type: none"> <li>• ‘you’d assume that in many cases that the child would feel a degree of responsibility to look after their brother or sister.’</li> <li>• ‘they would be dealing with it at a family level which is appropriate’.</li> </ul>

**Table III. Circumstances likely to increase risk of tissue matched children being subject to coercive pressure from parents or health professionals**

<i>Parental Pressure</i>	<i>Health Professional Pressure</i>
Earlier conflict between parents regarding whether to opt for transplant in sick child that is resolved in favour of transplantation.	Lack of independent health professionals for recipient and donor.
Where a parent of the tissue-matched child is the recipient.	Late withdrawal of agreement to act as a donor by a tissue-matched child at a time when conditioning in the recipient has commenced.
Informal tissue-typing processes and poor communication with family members about the implications of HLA-typing results.	